ROCKET SCIENCE

How Patient Data Informs Health Information

An evaluation of the impacts and challenges of including information about patient data in health charities' guidance

April 2022

Contents

Executive Summary

Evaluation aims

In August 2021 Rocket Science were commissioned by Understanding Patient Data (UPD) to evaluate the impact of the Data in Health Information Community of Practice. The Community of Practice (CoP) was established in May 2021 to support health charities to explain the use of patient data in the health information they provide and share learning and best practice. The key evaluation aims were to better understand:

How does explaining the use of patient data impact upon readers'[1] knowledge of the use of their data outside of their direct care?

How has the inclusion of/explanation of patient data impacted upon readers' behaviour in relation to the advice provided?

What has been the impact of the CoP approach for its members?

To what extent does the health information developed by CoP members follow the good practice identified in the How to Talk About Data project?

How does good practice guidance (provided by the Patient Information Forum, PIF) on explaining patient data impact the health information produced by PIF members/partners.

Methodology

A qualitative approach to the evaluation was taken. Adaptations were required in response to the changes CoP were able to make to health information and the challenges they faced due to resource and time constraints exacerbated by the Covid-19 pandemic. The methodology involved:

- The development of a health information scorecard tool with which to review how patient data is included and explained based on existing evidence
- Focus groups with members of the public exploring the impact of changes in health information (31 participants)
- A public online survey using the same A-B comparisons as focus groups (37 responses)

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[1] Reader refers to anyone reading health information which could be patients, carers or interested individuals.

- An online survey of PIF members to understand the impacts of changes in guidance (6 organisations)
- Interviews with stakeholders including representatives from CoP member organisations (6) and the UPD team (4)

Key findings

- Small changes in the way patient data is explained were noticeable and influential to the readers' perception of the health advice given. The inclusion of explanations in the use of patient data increased levels of trust and credibility in the information provided. The NHS was particularly seen as a trustworthy and credible source which enhanced transparency about how patient data is used.

- Including explanations helped the reader to understand that information was developed using data from people:

> "It is clear to you that this [example B] is informed by health data from other people." – Focus group participant

- Including explanations of patient data use was also linked with increasing the knowledge of the reader as to how data is used outside of people's primary care:

> "So as a patient reading this, I come to the conclusion that mine [data] may be used for similar purposes in present or future instances." – Focus group participant

- There was acknowledgement that increasing knowledge/data literacy is a process which may take time

> "It's gradual, over time, a few years down the line you can imagine that it [explaining the use of patient data] would lead to a shift in consciousness around how we interpret data." Focus group participant

- Explanations of how patient data is used prompted further curiosity among participants and increased the likelihood of the reader seeking further information.

- The community of practice approach is useful for members in both supporting change and networking. For some CoP members transitioning to including more data in health information required a shift in approach, and there remain opportunities to develop how patient data use is explained in health information, and appetite among CoP members to focus on this in future production of health information.

Recommendations for developing understanding in the use of patient data

The findings of this evaluation clearly indicate that explaining the use of patient data:

- increases understanding of how data is used outside of direct care,
- increases the readers' curiosity to find out more about how data is used
- increases the readers' perceptions of credibility and trustworthiness of the information provided.

Give these findings we would recommend:

1. Including explanations of the use of patient data in health information that is directly relevant to individuals at different points of care (e.g. diagnosis, treatment options, recovery, or maintenance of health).

2. The impact of changes to health information may depend upon the communities that the readers are from. For example, people from some minority ethnic communities report low levels of trust in the NHS. This could affect how health information and explanations of how patient data is used will be received[2]. We would recommend testing this within specific minoritised communities.

3. There were anecdotal concerns that inclusion of explanations of how patient data is used may increase concern about how patient data is used. This could be mitigated by also providing links to existing information in relation to anonymisation and pseudonymisation in research processes.

4. It is recommended that any future evaluation specifically include people who may experience accessibility issues or involve health charities such as those for people with sight loss or learning difficulties or disabilities to test whether there is any impact in accessibility as a result of including explanations of the use of patient data.

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[2] https://understandingpatientdata.org.uk/news/new-research-insights-black-south-asian-people-patient-data

Recommendations for supporting change

Whilst the CoP members faced challenges in making the changes to health information within the project timescales, we suggest that the community of practice approach and the type of support offered by UPD can be effective in supporting this change. The evidence of impact identified in this evaluation can serve to support a case for change with those who develop health information and guidance. As such we make the following recommendations:

- The findings of this evaluation are shared to promote the positive impact of small changes to health information providers and encourage future change in this area.

- The score card developed as part of this evaluation should be used by organisations in the future to review current health information and identify areas for development in the explanation of the use of patient data.

- Consideration should be given to the composition of any future communities of practice to ensure appropriate organisational representatives. Two members per organisation may be beneficial to provide continuity and internal capacity to implement change.

1. Introduction

4.1 Overview of the project

In May 2021 Understanding Patient Data (UPD) established a community of practice (CoP) with a range of national health charities, to share the learning and insights from UPD's previous How to Talk About Data project. A full list of membership organisations is included in table 1 below. Based on the learning developed from this previous project the objectives of the CoP were:

- Further test the insights developed by the How to Talk About Data project
- Support the health charities to add information explaining the use of data from patients in developing health information and guidance.

In August 2021 Rocket Science were commissioned by UPD to evaluate the impact of the Data in Health Information community of practice. The evaluation was specifically commissioned to mirror the collaborative approach of the community of practice with four specific aims:

1. How does explaining the use of patient data impact upon readers' knowledge of the use of their data outside of their direct care?
2. How has the inclusion of/explanation of patient data impacted upon readers' behaviour in relation to the advice provided?
3. What has been the impact of the CoP approach for its members?
4. To what extent does the health information developed by CoP members follow the good practice identified in the How to Talk About Data project?

Over the course of the evaluation it became apparent that a number of the CoP members faced challenges in both making changes to their health information and engaging with the evaluation despite their best efforts. Whilst these challenges were varied and are described in this report, they were undoubtedly exacerbated by the resource pressures that the on-going Covid-19 pandemic was placing on health services.

These challenges also required us to make changes in our methodology which included opening up focus groups to the general public and using more generic examples of health information developed by UPD. CoP members were unable to provide web analytic data as planned. This was largely because updated health information was not created or live on organisations' websites for a sufficient length of time to compare data before and after updates. This was therefore removed from the evaluation. Appendix 1 includes the original evaluation framework as conceived at the inception of the evaluation as well as the framework finally used. The evaluation methodology below expands on these research limitations.

The Patient Information Forum (PIF) was one organisation however that was able to make changes in their guidance which included recommendations on how to explain the use of patient data when developing health information. As such it was agreed an additional evaluation aim would be included relating to the work of the PIF, this was:

5. How does good practice guidance provided by PIF on explaining patient data impact the health information produced by PIF members/partners (in relation to including and explaining the use of patient data).

Table 1: List of community of practice members

Organisation Name
Asthma UK – British Lung Foundation (now Asthma + Lung UK)
Best Beginnings
Cystic Fibrosis Trust
MS Trust
Stroke Association
Patient Information Forum
National Autistic Society
British Heart Foundation

4.2 Methodology

In order to achieve the above aims, the evaluation took a mixed-methodological approach, which included:

- Development of a health information scorecard tool
- Assessment of original and updated health information submitted by Community of Practice members using a health information scorecard tool
- Survey of the general public

- Focus groups with the general public
- Interviews with Community of Practice members
- Interviews with Understanding Patient Data staff
- Attendance at CoP meetings.

Further details of the methods employed are provided below.

Development of health information scorecard tool

For the purpose of this evaluation health information is any advice, guidance, facts figure and/or statistics or other material produced by organisations relating to health conditions and/or treatment options. Health information can take many formats, including digital information provided on websites and apps, and paper-based information such as flyers and leaflets. In order to assess the changes made to health information by community of practice members, a scorecard tool was produced in the early stages of the evaluation. Themes and criteria for the scorecard were initially developed by Rocket Science drawing on existing guidance and resources generated by UPD, including materials produced through the How To Talk About Data (HTTAD) project, and the evaluation framework. Two members of the evaluation team independently generated criteria, and these were then compared and aggregated to create the final scorecard. Themes for the scorecard generated were:

- Inclusion of patient data
- Content
- Communication / prominence
- Availability.

Health information can be assessed against this framework, with a maximum score of 13, to understand strengths and areas for development with regards to the inclusion of information about patient data as a source of evidence in information. The scorecard was used during the evaluation to review health information and is also intended as an ongoing tool for future reviews of updated health information and newly developed health information.

Table 2 – Health information scorecard

Theme	Standard	Y	N
Inclusion of patient data	Patient data is included in the information		
	The source of patient data is cited following, or introducing, the guidance or health information e.g. "this work uses data provided by patients and collected by the NHS as part of their care and support"		
Content	Term *patient data* is used		
	It is clear that data used relates to people		
	Data used is relevant to the topic		
	Explanations are clear, concise and in plain English		
	There are links or sources of further information readers can go to, describing how their data is used beyond individual care		
Communication/prominence	The use of patient data is cited throughout (i.e. not appended or end noted)		
	How patient data is used to inform the guidance is explained within the text		
	Complex data is explained as it is cited		
	Pertinent points are highlighted or summarised		
Availability	Clear explanation that data from people has been used in developing the health information is available at key patient junctures (e.g. in treatment start, completion, or points of change)		
	Health information citing patient data is available in different formats including electronically, large print, and other accessible formats.		

Development of examples for survey and focus groups

Both the survey questions and the focus group discussion guides were designed to reflect the aims of the evaluation and the evaluation framework. In order to contextualise the research questions and improve the accessibility of these research tools for those who have limited experience with data and/or health information, simple examples of health information were used. Two examples were sourced from Public Health England and NHS health information by the UPD team, one related to sleep[3], and the other related to cancer[4]. For both pieces of health information, the UPD team created an updated version of the health information (version B) which differed from the original version (A). Example B included additional information about where the data in health information had come from, with specific detail that information came from people. These examples can be seen in section 4.

Survey and focus group sampling

An online survey was created using Survey Monkey and was distributed via members of the community of practice and Rocket Science social media throughout February and March 2022. In total, 37 participants responded to the survey. Demographic information of those taking part in each of these is available in appendix 2.

One of the CoP members was the Patient Information Forum (PIF). They work with organisations to support them in producing health information and generally do not work directly with the public. Therefore, Rocket Science produced a separate survey for PIF members which focused on the advice given to PIF members about the discussion of patient data within health information, and how likely they were to make changes to their health information. Representatives from 6 organisations responded to the survey.

Focus groups were recruited through Rocket Science social media and with support of the MS Trust, Health Data Research UK and Use My Data. Recruitment took place in February and March 2022, and focus groups were conducted in March via Microsoft Teams. In total 31 participants attended focus groups. Demographic information of those that took part is available in appendix 2.

Research limitations

The CoP faced a number of challenges in making changes to health information within the timeframe of the evaluation, including resource and time constraints exacerbated by increased demands and constraints on resources due to the Covid-19 pandemic. Relatively few CoP members were able to make changes to health information in the given timeframe.

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[3] https://www.nhs.uk/every-mind-matters/mental-health-issues/sleep/
[4] https://www.nhs.uk/conditions/cancer/

As a result of this, changes were made to the original methodology which limit the research. These included:

- **Recruiting focus group participants from the general public and other partners.** It was originally intended to obtain a representative sample of beneficiaries from CoP member organisations. Instead, focus group participants were recruited from the general public, and the evaluation team had limited control over the diversity of these participants. This may be particularly relevant in considering data literacy and it may be anticipated that those recruited from Use My Data and Health Data Research UK may have higher levels of interest and understanding in the use of patient data than the general public. Further focus groups which draw on a sampling frame to recruit representative participants are recommended.

- **Use of generic examples of health information produced by UPD from public health information**. Focus groups were designed to include examples of health information updated by CoP members, to draw on real examples that would be highly relevant to focus group participants. Instead, generic versions of health information were used, and updated versions were produced by UPD to provide examples of explanations of patient data used. Therefore, information was not necessarily relevant to focus group participants. Examples based on health areas that are of interest to many members of the general public (sleep and cancer) were selected to mitigate this risk and ensure health information was set in a context that would likely be familiar to focus group participants.

- **Unavailable web analytics analysis from the evaluation.** The challenges of updating health information meant plans for analysis of reader interactions (e.g. click through to links) with patient data was not possible. Further analysis of how readers interact differently with electronic health information and available information about patient data is recommended.

2. Changes made to health information as a result of the community of practice

Key findings

- Of the organisations that shared changes to health information, these mainly focussed on including data and statistics to support the statements made in the health information. For some CoP members, transitioning to including more data in health information required a shift in approach, suggesting that CoP members had varied starting points when joining the group.
- In a small number of cases there were new direct references to patient data as a source for statistics. There remain opportunities to develop how patient data use is explained within the updated health information shared.

Organisations who had made changes to their health information shared pre-change and post-change versions of this information with the evaluation team. These versions were reviewed using a health information scorecard (see section 1.2) and pre- and post- scores were compared to explore the improvements made in health information as a result of engagement with the CoP. Overall, relatively few organisations shared pre- and post- health information with the evaluation team as most organisations did not complete updates to their health information during the timeframe of the evaluation.

As an example, Table 3 below shows the pre- and post- comparison of 3 pieces of health information. Each piece of information is scored out of 13.

Table 3 - Scoring of pre- and post- health information, change in score, for three pieces of health information

	HI* 1	HI2	HI 3
Pre-score /13	4	3	4
Post-score /13	6	7	6
Change	+2	+4	+2

(*) HI = health information

Overall, these changes mainly focussed on including data and statistics to support the statements that were made in the health information and including citations to evidence sources. In a small number of cases, there were new direct references to patient data as a source for statistics (see Table

4 above). As can be seen, scores across all three pieces of information have increased as a result of changes made but there remain opportunities to develop how patient data is explained in each case. These opportunities are predominately in explaining that data from people has been used in development of the health information. Table 4 and Table 5 both show examples of changes made to health information by a member of the Community of Practice. Barriers to making changes to health information were explored as part of the final sense-making session with CoP members and can be found in chapter 7. When updated health information was shared with UPD by Rocket Science, UPD redoubled their efforts to meet with and provide support to CoP members.

Table 4 – Example of change in health information produced by Community of Practice member (1)

Pre-update	Post-update	Scoring	Pre	Post
Tragically, three people die every day because of asthma attacks and research shows that two thirds of asthma deaths are preventable.	Tragically, three people die every day because of asthma attacks **and a major study into asthma deaths (The National Review of Asthma Deaths 2014) which looked at patient data from hospitals and GP practices**, found that two thirds of asthma deaths are preventable.	Inclusion of patient data	0	2
		Content	1	4
		Communication / prominence	N/A	N/A
		Availability	N/A	N/A

Table 5 – Example of change in health information produced by Community of Practice member (2)

Pre-update	Post-update	Scoring	Pre	Post
Shisha smoking, also called hookah or waterpipe, also contains tobacco. The smoke goes through water but contains the same dangerous chemicals and is	Shisha, also called hookah, narghile, waterpipe, or hubble bubble, is a form of smoking tobacco. It's addictive and harmful for your health. Smoking shisha can at least double your risk of developing lung cancer and could also increase your risk of other	Inclusion of patient data	0	1
		Content	0	3
		Communication / prominence	N/A	N/A
		Availability	N/A	N/A

just as harmful as normal cigarette smoke.	cancer types, such as mouth or stomach cancers.[1,2]. A 2016 analysis of several studies[3] has shown that during just one session of shisha smoking, a person can take in the same amount of tar as 25 cigarettes, the same amount of carbon monoxide as 11 cigarettes and the same amount of nicotine as 2 cigarettes.[4] [1] NHS – Paan, bidi and shisha, https://www.nhs.uk/live-well/quit-smoking/paan-bidi-and-shisha-risks/ [2] CRUK – Shisha, betel leaf, paan and other tobacco, www.cancerresearchuk.org/about-cancer/causes-of-cancer/smoking-and-cancer/shisha-and-other-types-of-tobacco [3] Primack B et al. Systematic Review and Meta-Analysis of Inhaled Toxicants from Waterpipe and Cigarette Smoking [4] NHS – Paan, bidi and shisha			

3. Existing perspectives on the inclusion of patient data in health information

Key findings

- Focus group participants (31) had mixed levels of data literacy. Within this group, there was some scepticism about use of patient data and the group thought that few members of the general public are aware of who accesses patient data.
- Responses of survey participants (37) suggest a relatively high level of data literacy within the group. Most understood how health information draws on patient data and valued having health information which is evidence-based. However, despite high data literacy, relatively few understood how their health data is used outside of their individual care.
- CoP members felt that the level of understanding by members of the public as to how and when patient data is used is likely to be low. Some thought people do generally value patient data and that including statistics in health information is ‘powerful’. Others discussed the fear of data that some people have which can increase suspicion about how their data is being used. Factors which influence trust of patient data mentioned included the organisation generating data and language used around inclusion of data.

Both survey and focus group participants were initially asked questions in relation to their understanding of how patient data is used and for their views on this. These questions were posed to ensure shared understanding of terms used and to clarify the pre-existing understanding of participants of patient data and its use in health information.

Findings from focus groups

Public focus groups were recruited to through Rocket Science social media and with support of the MS Trust, Health Data Research UK and Use My Data. As a result, health data literacy was mixed, with a number of focus group participants directly working with, or having high levels of knowledge about, the use of patient data, whilst for other group participants this was not a familiar area. This was reflected in discussions with some group participants able to describe in detail anonymisation and pseudonymisation processes whilst others were not aware of these processes and how they are used to gather patient data.

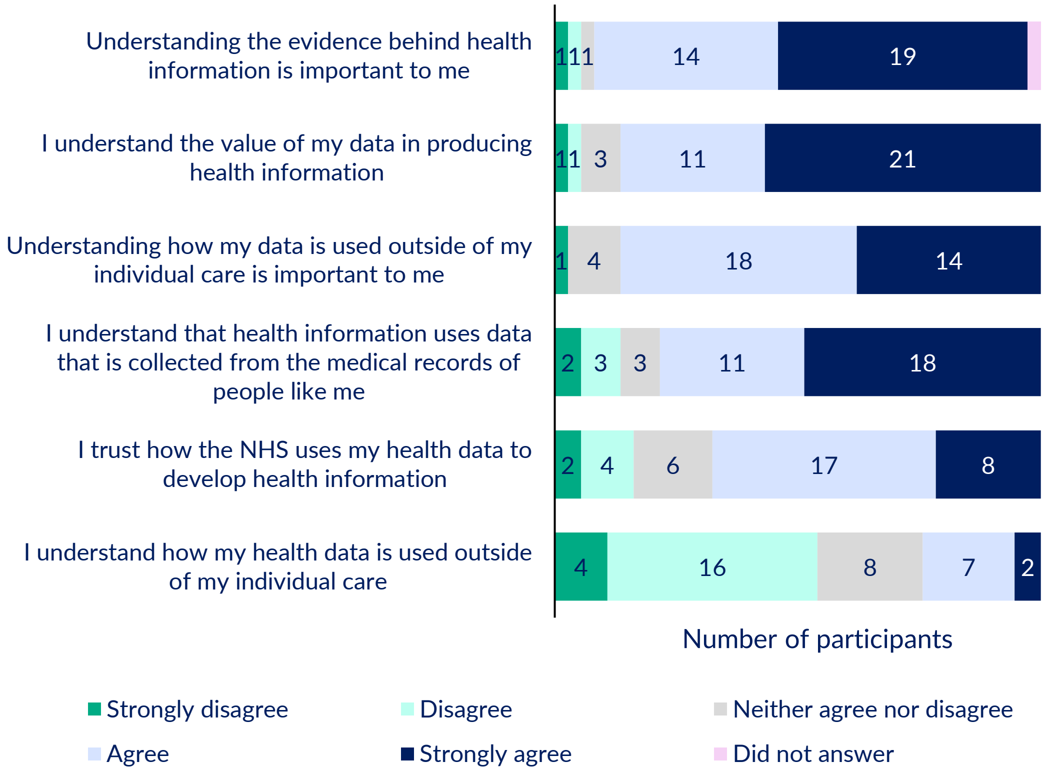
Regardless of existing levels of knowledge about the use of patient data there was a scepticism about its use across the focus groups. This ranged from what one person described as *“mis-steps”* in the use of data, frustration at how difficult some found it to opt out of for example the General Practice Data for Planning and Research programme, to concern about the use of use of DNA and tissue samples. Whilst some in the group were knowledgeable in this area, they understood that this was not necessarily true of the wider public:

> *"Very few people are aware of who accesses data outside of GP's and healthcare providers. It's not clear who is exposed to the data."* Focus Group participant

Findings from survey

Survey participants were initially asked to respond to a series of statements about patient data. These questions were asked to gain insight on the level of understanding about patient data and its use in health information within the group of survey participants. Responses to these questions are seen in Figure .

Figure 1 – Survey participants' understanding and perception of the use of patient data in health information (n=37)



Results suggest a reasonably high level of data literacy existed within the group of survey participants. Most participants understand how health information draws on an evidence base from patient data, value having health information which is evidence based and understand that their data is used in producing health information. Fewer participants said they trusted how the NHS uses their health data, with only 68% agreeing with this statement. The most mixed response was given to the question 'I understand how my health data is used outside of my individual care' with only 27% agreeing with this statement. This suggests that while participants understand that patient data in health information draws on data from people like them and know that their data is valuable in producing health information, they do not have a broader understanding of ways that their health data is being used outside of their individual care. This however may also represent a selection bias given the sources of recruitment for the evaluation. See research limitations above for further details.

Perspectives of CoP members

Generally, CoP members felt that the level of understanding by members of the public as to how and when patient data is used in health information would be low. Some felt that people would not realise a lot of their data is already being collected or even think about where data has come from, unless they were from a research background.

> *"Honestly, I don't think this is something that people think of in this context. If they put themselves forward for a clinical trial, they know their data will be used, but when making [a health related] decision, the fact that other people are involved in this [data] isn't quite as immediate to them."* – CoP member

Despite a lack of understanding it was believed that the inclusion of data and statistics in health information because *"statistics and numbers are always powerful in health information and campaigning"*.

Others felt that there would be a lot of misunderstanding or misinterpretation amongst the general public, rather than just not knowing anything about it. CoP members expressed that some people are fearful of data, amplified by discussion of data in the media. There were also feelings that increased awareness of how patient data is used in health information could make people *"more suspicious"* and lead them to *"feel more protective if they are aware their data is being used"*. One member gave the topic of Covid vaccinations as an example stating that:

> *"It made the whole environment more difficult to talk about data. People are now so scared of it, and they don't trust it because they are so constantly bombarded and confused."*- CoP member

A number of CoP members mentioned the controversy around General Practice Data for Planning and Research[5], explaining that this reduced people's confidence in their knowledge about how patient data is used, and reduced their trust in the systems that use patient data. One member explained this incident *"brought home the importance of this work"* because it showed people wanted much clearer explanations of how their data was being used, and the risks and benefits associated with this.

CoP members felt the language used around inclusion of patient data in health information influenced how people felt about it. Using terms such as 'research study' was considered by one member to be associated with concerns about data being sold:

> *"People see research words and jump to a commercial place, [they think an organisation has] sold out. The language used is important."* – CoP member

Linked to this, CoP members felt the organisation from which the data or the health information was being generated influenced people's perceptions of the health information, particularly around confidence and trust:

> *"People seem to have very different perceptions of the NHS and big pharma. We all know it's not that clear cut."* – CoP member

CoP members were unsure of how many people would actually use click through links to gain further evidence within health information, however they felt it was important to include these as they knew some of the readers of their health information found them helpful. When discussing one of the key evaluation aims, whether explaining the use of patient data would alter people's attitudes towards or intention to act on the health advice, there was some scepticism amongst CoP members. It was felt that this might particularly be the case in conditions that people feel they experience individually.

> *"An individual person with [this condition] is less likely to regard themselves as a part of a particular group [that might be referred to in health information]".* – CoP member

CoP members also identified that other changes made to the health information at the same time, such as the inclusion of case studies or personal accounts may also change reader perceptions and behaviour.

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[5] General Practice Data for Planning and Research (GPDPR) - NHS Digital

4. Impact of changes to health information – perspectives from survey

Key findings

- Survey questions asked participants about the impact of updating health information to demonstrate where data comes from, specifically that this data comes from people. Original and updated versions of real health information were provided to participants as a focus for these questions.
- Overall, participants expressed preferences for the updated health information which includes references to NHS data and provides clear explanation that this data comes from people. They explained that this drew their attention to the information and made them more likely to trust the information and to share it with others. Knowing that data came from the NHS had a positive influence on the perception of the information.
- Participants were divided about whether including this additional information makes it easier to understand. There is a balance to be struck between including the evidence base and source of data and including more copy which can make information less easy to understand and lose the reader's attention.
- Participants thought that including information on where data has come from in health information can help to shift a prevailing narrative around the potential risks of sharing data, by emphasising that data *'drives a lot of the NHS'*.

This chapter reports on findings from survey questions which explored the impact of updates to health information which demonstrate that the data underpinning the evidence comes from people. Specifically, updated versions of two pieces of health information; one related to sleep, and the other related to cancer, were used as examples, and participants were asked for their opinions on the impact of the changes.

37 responses were received to the survey in total. Detail on the demographics of those who responded is available in appendix 2.

Survey participants were asked to read two versions (A and B) of the same piece of health information and then to give their thoughts on the differences between the two versions. In both iterations of this exercise example B contained information about the data underpinning the statements in the information, with specific reference to this data coming from people. Table 6 and Table 8 below show the examples that were used in both the survey and in focus groups.

It should be noted that given the relatively small sample of survey participants (n=37) and the methods of distribution (promoted via health charities and Rocket Science social media) participants are likely not representative of the general public. There is likely a selection bias in the sample with those who already have an interest in, or understanding of, patient data due to their engagement with health charities. As can be seen in appendix 2 there is also a substantial under-representation of men within survey responses.

Health information about sleep

Table 6 – Two versions of a piece of health information about sleep used in survey and focus groups[6]

A	B
We all have evenings when we find it hard to fall asleep or find ourselves waking up in the night. How we sleep and how much sleep we need is different for all of us and changes as we get older. Sleep problems usually sort themselves out within about a month. But longer stretches of bad sleep can start to affect our lives. It can cause extreme tiredness and make usually manageable tasks harder.	We all have evenings when we find it hard to fall asleep or find ourselves waking up in the night. How we sleep and how much sleep we need is different for all of us and **we know from data held by the NHS about people's health that this** changes as we get older. **The data also tells us that** sleep problems usually sort themselves out within about a month. But longer stretches of bad sleep can start to affect our lives. It can cause extreme tiredness and make usually manageable tasks harder.

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[6] Note: changes to health information were not bolded in the survey and bolding is used here for illustrative purposes

Table 7 – Survey participant preferences for versions A and B, health information about sleep

Sleep	A	B
Easier to understand?	56%	44%
Trust more?	28%	72%
More likely to share?	39%	61%
Draws attention to health info?	28%	72%
More likely to follow?	29%	71%

Overall, slightly more participants thought example A, rather than B, was easier to understand (56% A, 44% B). Those who selected A thought that it was *'straight to the point'* and that brevity and *'sharper language'* made it more understandable to the *'lay person'*. Those who thought B was easier to understand said it was more 'precise' with one participant saying, *'I'm a scientist and prefer when assertions are justified'*.

Participants were substantially more likely to trust the information in example B than in example A (28% A, 72% B). Most who selected B said the increased trust was due to the evidence source provided, with some saying that they specifically valued knowing data came from the NHS. None specifically said they valued knowing data had come from people. One person who was more likely to trust A said, *"Use of the word data and NHS is somewhat dubious"*.

Participants were also more likely to share example B compared to example A (39% A, 61% B). Reasons for this were mostly that explaining the source of the data gave the evidence more credibility.

Participants felt example B also drew more attention to the health information compared to example A (28% A, 71% B). Reasons for this were similar to the responses above, with many participants explaining that mentioning the data or evidence base, and particularly that the data came from the NHS, drew attention to the information. One participant noted that the claims in version A were *'unfounded'*. However, some mentioned that without citing the source of the data, the impact of this was limited.

Participants thought they would be more likely to follow the health information in example B than example A (29% A, 71% B), again stating that the evidence base provided was the reason why they were more likely to do this and that they considered the NHS a 'reliable source'. Those who selected example A stated that they felt this was easier to understand, *'said clearer (sic.) and with less words'* and therefore they would be more likely to follow this.

Health information about cancer

Table 8 - Two versions of a piece of health information about cancer used in survey and focus groups

A	B
Cancer is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs. Cancer sometimes begins in one part of the body before spreading to other areas. This process is known as metastasis. 1 in 2 people will develop some form of cancer during their lifetime. In the UK, the 4 most common types of cancer are: • breast cancer • lung cancer • prostate cancer • bowel cancer	Cancer is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs. Cancer sometimes begins in one part of the body before spreading to other areas. This process is known as metastasis. Based on NHS data collected from people's medical records, we know that 1 in 2 people will develop some form of cancer during their lifetime. We know from this data that in the UK, the 4 most common types of cancer are: • breast cancer • lung cancer • prostate cancer • bowel cancer

Table 9 - Survey participant preferences for versions A and B, health information about cancer

Cancer	A	B
Easier to understand?	43%	57%
Trust more?	18%	82%
More likely to share?	30%	70%
Draws attention to health info?	29%	71%
More likely to follow?	17%	83%

Responses to the example based on Cancer were similar to those on the sleep example, with slightly more participants considering example B favourable to A across all 5 questions posed.

A notable difference from the sleep-based example is that slightly more participants found example B easier to understand than example A (43% A, 57% B). Reasons given for this included that the basis for the statements was explained, with one person saying '*[example B] explains clearly that the information is based on people's medical records, and I feel that A is more for quick reading*'. Those who thought A was easier to understand gave similar reasons to those given for the sleep-based example, including:

> *"Less to take in regarding an emotive topic"*
> *"Less (sic) words and doesn't make me think about the issues with NHS data"*
> *"Both are easy to understand but A is briefer"*
> *"The narrative seems to flow better and seems more concise."*

Overall, many participants said that stating the evidence base, and specifically knowing the data came from the NHS had a positive influence on their perception of the information, while a minority said that knowing data came from the NHS reduced their likelihood of trusting, sharing, or following information. No participants specifically mentioned the impact of knowing the data came from patients on their likelihood of understanding, trusting, paying attention to, sharing, or following the health information, in the free text responses to questions.

Participants were also asked some questions specifically about example B in both cases, to further understand the impact of including information about where data had come from. Results can be seen in Figure ,

Figure and Figure .

Figure 2 – Impact of including additional information about source of data in example B, sleep (n=37) (to what extent does the additional information in version B)

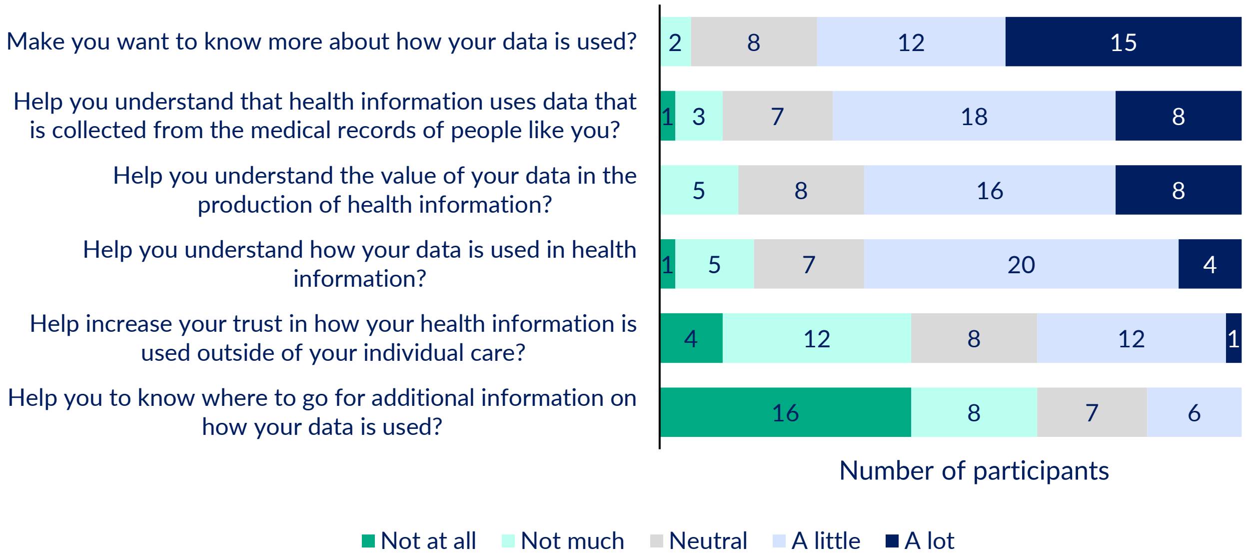


Figure 3 - Impact of including additional information about source of data in example B, cancer (n=36) (to what extent does the additional information in version B)

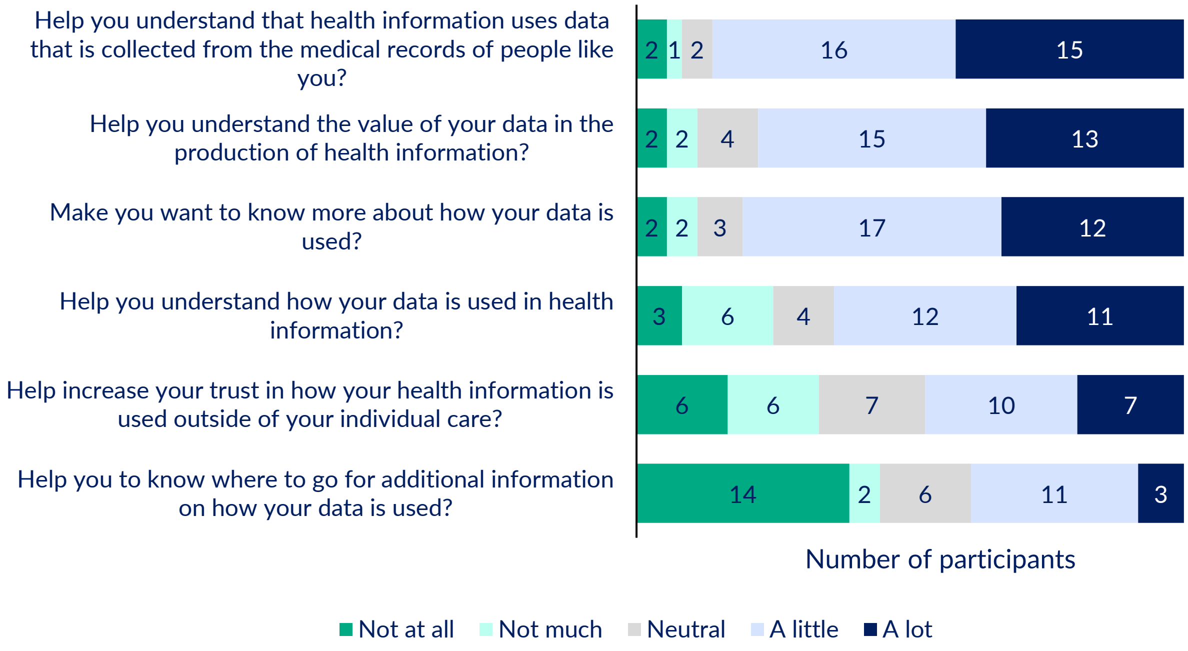
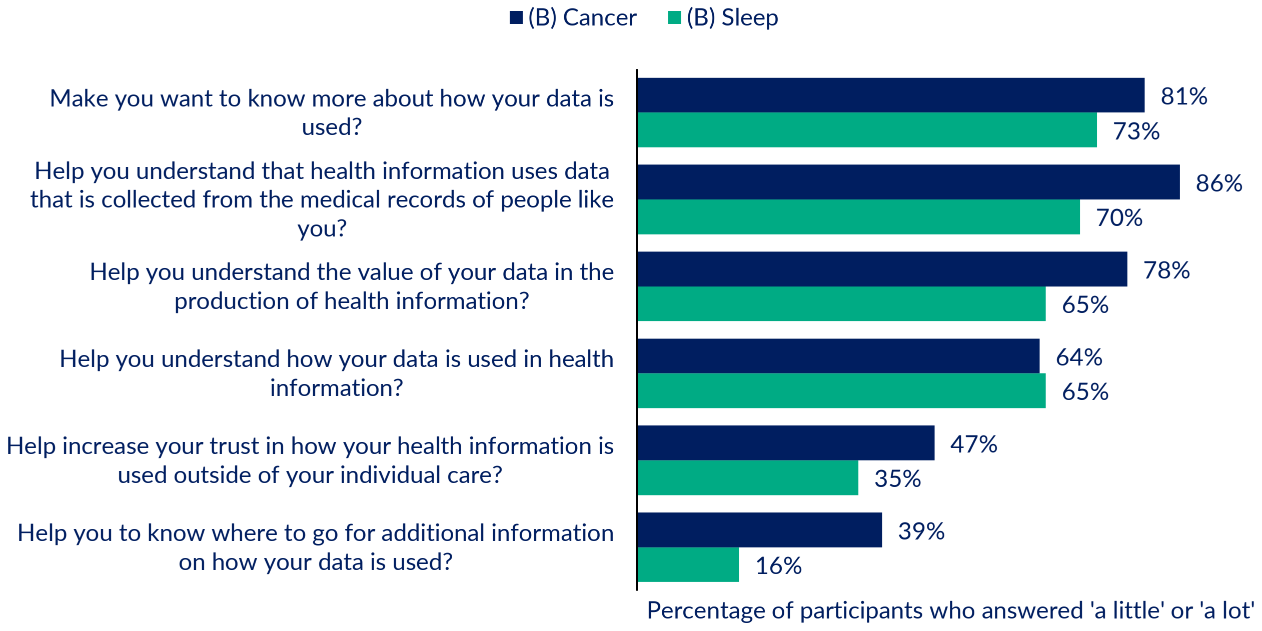


Figure 4 - Impact of including additional information about source of data in example B, sleep, and cancer (to what extent does the additional information in version B)



Overall, the additional information provided made most participants want to know more about how their data is used, with 77% answering ‘a little’ or ‘a lot’ to this question across both examples. It is not possible to directly infer whether this is positive or negative, e.g. a result of higher engagement with data or reflective of concern about data sources. However, qualitative responses throughout the survey suggest that a minority of participants wanted to know more because they are concerned about patient data use, and a majority want to know more through curiosity about patient data use and wanting to further understand the evidence base. The additional information helped participants understand that health information uses data that is collected from patient medical records (78%). Including this information also helped most participants understand the value of their data in the production of health information (72%) and helped them understand how their data is used in health information (65%). However, less than half (47%) thought that the information increased trust in the use of health information outside of individual care. Few (28%) thought it helped them know where to go for additional information on how data is used, which was perhaps to be expected, as references were not provided with the text.

Participants were asked to explain the responses they gave to this series of questions. Responses further demonstrate an overall preference for example B in both health information about sleep and cancer. Themes that emerge included:

- Noting that there was no ‘signposting’ to the source of data and that version B would have been improved if it had included a reference to the data

- Reiterating the careful balance between including the evidence base and source of data, and including more copy which can make information less easy to understand and can lose the reader's attention:

> [Referencing example B, sleep] *"The explanation about the use of the data is not explicit… the sentence merely implies that my data are used in this way. That said, I don't think it would be all that helpful to explain the use of data here… because more copy on the page makes people switch off!* - Survey participant

- Briefly mentioning the source of data opens up more questions for some readers:

> *"In option 2 [B] the language seems more evidenced but a vague reference to data raises more questions than it answers - what about systematic reviews… I want full footnotes, or I want it to be implied that it is the best possible research.*" - Survey participant

- Trust in the NHS as a source of data:

> *"I like things to be based on truth and because the NHS is generally not for profit, it's more likely to be truthful because there is no hidden agenda"* – Survey participant

Survey participants were finally asked two questions about the general benefits and drawbacks of including information on where data has come from in health information. Of those who responded to these questions (n=28) **96%** identified at least one benefit of including this information. **61%** identified at least one drawback.

The following themes emerged about the potential benefits of including this information:

- Improving **trust** in the information and the perceived level of credibility
- Increased **transparency** about reasons why data is collected
- The importance of making people aware of the **value** of using patient data
- Including this information can help shift a prevailing narrative around the potential risks of sharing data, by emphasising that data *'drives a lot of the NHS"*

> *"[Including this information] makes it credible, reliable, and convincing."* – Survey participant

“Improves trust in both the information (as provides a source) and the act of collecting health data, as this appears to legitimise it.” – Survey participant

Participants also noted the importance of providing sources when this type of information is included:

“If it is going to be mentioned, then further explanation is required. The source of any data is always valuable in ascertaining how accurate the information may be.” – Survey participant

The following themes emerged about the potential drawbacks of including this information:

- Risk of **losing attention** of those reading information when additional information is added
- Risk of **reducing accessibility**
- Risk of **causing concern about how medical data is being used** if appropriate sources and additional information are not easily accessible.

“It may cause concern if people weren't aware their medical records were used for these purposes, if there isn't any accompanying info or links to find out more about how their data is used.” – Survey participant

“I review patient website pages and less is more.” – Survey participant

“May make the piece more difficult to understand or longer do people less likely to read the piece” – Survey participant

“You have to be careful how you phrase it, and it draws attention to the potential issues with NHS data, e.g.... bias, representability of the population” – Survey participant

5. Impact of changes to health information – perspectives from focus groups

Key findings

- Providing additional detail on where data has come from in health information was considered to make the advice more credible and accurate, giving it more ‘authority’
- Citing the NHS as a source of data was thought to improve transparency about how patient data is used and about how health advice was developed. This improved transparency was linked with building trust in the advice. Including a reputable source of data also contributed to enhancing credibility.
- Some thought that including information about patient data as a source of evidence raised awareness of the use of data
- Providing this additional information increased focus group participants’ curiosity about how data is used and how data was collected. Providing links to additional information was suggested to balance accessibility and thoroughness
- Accessibility was a common and spontaneous discussion in all focus groups, with participants typically talking about shorter pieces of health information as being more ‘user friendly’. However, only a small minority of focus group participants stated a preference for the original versions of health information which did not include information about data and where it had come from.

This chapter reports our findings relating to how explaining the use of patient data in health information impacts upon the readers’ understanding of how patient data is used for this purpose. These findings are from five focus groups facilitated in February and March 2022. In total 31 participants attended focus groups. Demographic information of those taking part is available in appendix 2. The health information relating to sleep and cancer described in section 1.2, above, were used in all focus groups. As previously described, the groups were recruited with the support of a health charity member of the CoP (MS Trust) and organisations working in health research and campaign groups in the field. As a result, health data literacy was mixed, with a number of focus group participants working with, or with high levels of knowledge about, the use of patient data whilst for others this was not a familiar area.

4.3 Impact on *perceptions* of how patient data is used

As described in section 2, overall there was a scepticism about the use of patient data across the focus groups. This was borne out of having direct experience of the field or from news and media stories relating to the use of patient data. Using the A and B examples the groups were initially asked to reflect on whether changes made any impact upon their perceptions of how data is used. The following themes emerged.

Transparency and trust

It was felt by a substantial number of focus group participants that citing the NHS as a source of data in example B provided a greater degree of transparency as to both how patient data is used but also how the health advice was developed.

> *"[example A] makes me think 'who's telling me this, why do they know this? Show us the data!"* – Focus group participant

This increased transparency was itself linked to building trust with the advice and its accuracy. That the NHS was cited was particularly useful for a number of participants who saw the NHS as a trusted and familiar source and the use of data by private companies was often unfavourably compared. That the data was from the NHS also enabled some to draw conclusions as to the relevance of the advice and that it was drawn from UK, and not international, data also increased perceptions of relevance.

> *"I appreciate transparency, I always question information no matter who produces it. [Transparency] builds confidence and trust, even if it's just a few words"* – Focus group participant

For a minority of participants, the inclusion of the NHS citation however was considered unhelpful. This was particularly the case where there were pre-existing concerns about the use of patient data and where it was felt that this inclusion may cause additional *"anxiety"* about how data is used.

Credibility of advice

Building on transparency and trust, the additional text in example B was also associated with making the advice more credible, with a number of participants describing it as having more *"weight"* and *"authority"* as a result of the advice being perceived as more *"accurate"*, *"complete" "detailed"*, *"fact* *based" and "data driven"*. This contrasts with comments about example A which were often that the advice felt *"anecdotal"* or *"without any evidence"*.

Credibility of information was closely linked with its source in a number of the focus groups. Those who saw example B as being more credible attributed this to the citation of the NHS, a source which participants saw as being credible and authoritative. This contrasts with one person's perspective that likened example A to advice found in magazines (Men's Health was the example given). Other credible sources of information cited in groups included broadsheet newspapers and organisations such as National Institute of Health Research. The perceived credibility of health charities was dependent upon their authority on a specific topic and assumptions of rigour based on the organisation's reputation, as perceived by the reader.

4.4 Impact on *understanding* of how patient data is used

Focus group participants were asked when comparing the A and B examples whether there was any impact on their understanding of how patient data is used.

Whilst a number of participants were already aware of the use of personal data it was felt by many that example B highlighted the research and science behind the development of health information as well as raising awareness of the use of data. When discussing example B participants were able to surmise that the NHS specifically included GP's and/or hospitals as sources of data and in some instances, this would be from people with certain health conditions.

> *"It is clear to you that this* [example B] *is informed by health data from other people."* – Focus group participant

> *"So as a patient reading this, I come to the conclusion that mine [data] may be used for similar purposes in present or future instances."* – Focus group participant

One group member suggested that the additional explanation in example B would be beneficial for increasing health literacy generally because of the explanation given, whilst another reflected how although the changes in example B were small the longer-term impact may be in increasing the wider public's understanding of the use of patient data.

> *"It's gradual, over time, a few years down the line you can imagine that it would lead to a shift in consciousness around how we interpret data."* – Focus group participant

For many in the groups, whilst the additional explanation in example B was helpful, even more information about the data was desirable, but there was often acknowledgement that this required balance with accessibility of the overall information. The use of hyper-links to other sources of information was seen as a way of resolving this issue.

4.5 Impact of changes on reader behaviour

In addition to perceptions and understanding focus group participants were also asked to reflect on whether there were differences in how they may interact with or follow health advice between the four examples given.

Seeking out information to increase understanding

A consistent theme across the focus groups was the engagement with the data that example B provoked. Commonly this was a desire in the group participants to know more and that the provision of a small amount of explanation made them more inquisitive and curious about how data is used

> *"There may be more action to find out how my data was used based on* [example] *B's wording."* – Focus group participant

> *"It* [example B] *would make me want to read further – to go another step."* – Focus group participant

For some this was due to there not being enough information on the data behind the advice, with some group participants wanting details in relation to sample sizes, references, and demographic information. The need for demographic information was particularly linked to the representativeness of samples on which information is created and a concern of a perceived lack of data from minoritised communities. In the sleep example, questions were raised as to whether this was information taken from primary care or specialist sleep clinics, for example.

> *"I think that a lack of information…would be negative for people as they would want to know more about the use of data, but positive in the sense that people will be aware that data is being used."* – Focus group participant

Providing links to this additional information was commonly raised and suggested to balance accessibility and thoroughness. One person stated:

> *“[I} don’t usually look at links, but it’s reassuring that they are there.”* – Focus group participant

Impact on attention to and action on health advice

The focus groups did not offer perspectives on whether either example would be more or less likely to influence their behaviour. It should be noted that the information used did not make specific recommendations and the advice was not contextually relevant for participants. Were this research to be repeated with relevant health information, as had been the original intention with readers of CoP member health information, the findings may be different.

However as noted above greater degrees of trust and credibility were given to those which explained the use of patient data from which intention to act may be inferred. It would be useful to further test this with health information that is directly relevant for those participating in the research, and which recommends actions.

Issues of accessibility

Although accessibility was not an area specifically explored in focus groups it was a common and spontaneous topic of discussion in all five groups. It was often noted that accessibility and particularly the length of health advice is a significant consideration and that shorter pieces are seen as more *“user friendly”*. Despite this however just two focus group participants stated a preference for example A, even when conceding that example B was more trustworthy, credible, or complete. Average reading ages and the potential for people not to read even slightly longer advice was a concern for some participants.

6. Changes to PIF guidance

Key findings

- The Patient Information Forum (PIF) provide guidance for organisations that create health information. Through their participation in the Community of Practice (CoP) they updated member guidance and created new resources for their public-facing website, focussing on explaining the use of patient data."
- PIF aimed to be both accurate and informative without overloading members with information when making changes.
- With their public webpage, PIF aim to target individuals who don't have existing knowledge or the time to do further research, and therefore a focus on accessibility was important.
- The aim of changes was to influence PIF members to edit health information and therefore to increase readers' understanding of the use of patient data in health information and their trust in this. Based on the findings of the earlier How to Talk About Data project, it was expected impacts would likely arise by emphasising the role of real people within health information.
- PIF reflected that impacts of changes would depend on the communities targeted, as some communities have less trust in institutions and are not used to being represented within health information, and that in these cases, explaining that patient data included people from within their community is important.
- Surveyed PIF members (6) were mostly aware of the PIF guidance on how to explain the use of patient data in health information. Some had already made changes to their health information in line with this. PIF members were mostly neutral about their likelihood of updating their health information to include this in the near future, with most stating this is not a priority for their organisation. This suggests there is opportunity for additional explicit guidance on the value of this for PIF members.

The Patient Information Forum (PIF) is a membership organisation for organisations that create health information. They do not produce health information themselves but provide guidance to those who do. The PIF TICK, which is administered by PIF, is a *"quality mark for health information in the UK"*. As participants in the CoP, the member involved was interviewed for the evaluation. Subsequently a survey of PIF members was also conducted to evaluate the impacts of the changes made to their guidance on 'Finding and referencing evidence sources'.

4.6 Changes to PIF health information guidance

Through their participation in the CoP, PIF made a number of changes in both their public facing website and guidance for members focussing on explaining the use of patient data.

The webpage 'What is patient data?' was created to provide explanation to members of the public about patient data and its uses, provide examples, and highlight the importance of sharing patient data. The PIF member of staff engaging with the CoP explained that this *"is quite different to the information we normally produce, [it was] produced as an extra bit of work as a result of this project."* PIF had the challenge of figuring out how in-depth to go within a 'one pager' as *"we were trying to be accurate and informative without overloading people with information"*, noting that *"if you include too much, it becomes completely inaccessible"*. They went on to explain that it is particularly important for the webpage to target members of the public who don't have existing knowledge, or the time to do further research. The webpage has been viewed 168 times in 5 months (since being published in October 2021 to March 2022) and is the ninth most popular page on the PIF TICK site.

The most substantive changes in relation to the explanation of the use of patient data are found in *'Finding and referencing evidence sources'* (revised October 2021). Therefore, this guidance has been analysed for this evaluation.

The relevant changes in the 'Finding and referencing evidence sources' guidance are summarised in the table below with changes to text highlighted in italics.

Table 10 – changes made to PIF guidance Finding and referencing evidence sources.

2019 Guidance	2021 Guidance
Grading and critical appraisal of evidence The Oxford Centre for Evidence-Based Medicine (OCEBM), The SORT system (Strength of Recommendation Taxonomy) and GRADE (Grading of Recommendations Assessment, Development and Evaluation) are used for grading evidence and often used in journals and clinical guidelines.	Grading and critical appraisal of evidence The Oxford Centre for Evidence-Based Medicine (OCEBM), The SORT system (Strength of Recommendation Taxonomy) and GRADE (Grading of Recommendations Assessment, Development and Evaluation) are used for grading evidence and often used in journals and clinical guidelines.

Critical appraisal assesses the trustworthiness, relevance, and results of published papers. The Critical Appraisals Skills Programme (CASP) has a set of tools to use when reading research. It is important to be honest with your readers about the reliability of evidence. It will help them understand how believable or reliable the results are. Aim to include a full list of evidence sources within your information resource.	Critical appraisal assesses the trustworthiness, relevance, and results of published papers. The Critical Appraisals Skills Programme (CASP) has a set of tools to use when reading research. *How to talk about data* *Be honest with readers about the quality of evidence and the reliability of recommendations. Make clear if the data is drawn from real people, for example clinical trials or patient registries. People may be more likely to engage with this type of data and see the wider value of data sharing.*
Communicating the quality of evidence to users Health information should be based on high-quality research evidence. However, this will sometimes be problematic because there is only limited evidence, or evidence is of low-quality or has conflicting findings. Studies have shown people want to know whether they can be 'sure' about risk/benefit statistics quoted in evidence. They want to understand the quality of the evidence. It is important to be honest with your readers about the reliability of your evidence. Giving your readers some indication of how good the	Communicating the quality of evidence to users *It is important to be explicit that data gained from people helps inform health information – be it a research study or patient records. We cannot assume readers understand data is from 'real people' living with their condition. Making this clear may make readers more likely to engage with the data and understand how patient data is used.* Health information should be based on high-quality research evidence. However, this will sometimes be problematic because there is only limited evidence, or evidence is of low-quality or has conflicting findings. Studies have shown people want to know whether they can be 'sure' about risk/benefit statistics quoted in evidence. They want to understand the quality of the evidence. It is important to be honest with your readers about the reliability of your evidence. Giving your readers some indication of how good the

evidence is will help them to understand how believable or reliable the results are. If the evidence is really poor (there is only a limited number of very small studies, or you only have an expert's opinion), you may need to question whether you include it at all. However, if it is something that is important to your audience, you may need to. The key is to be open. Be clear that the results are not definitive.	evidence is will help them to understand how believable or reliable the results are. If the evidence is poor (very small studies or expert opinion) should you use it? If it is important to your audience, you may need to. Be honest. Be clear results are not definitive.
Ensure users can easily find the sources Aim to include a full list of your sources of evidence within your information resource wherever practical. It shows readers that your information is accurate and evidence-based. Make sure you readers are aware of how they can contact you to obtain sources.	Signposting and referencing *It is important to ensure users can easily find the sources of evidence you have used.* Aim to include a full list of your sources of evidence within your information resource wherever practical. It shows readers that your information is accurate and evidence-based. Make sure you readers are aware of how they can contact you to obtain sources.

As can be seen, a number of changes were made to the guidance, these included guidance on quality of data and referencing sources both of which were of interest in our focus groups. Critically for this work, explicit guidance on ensuring clarity on the use of data from people, including patient records, was included in the section about communicating evidence.

4.7 PIF perception of the impact of these changes

PIF explained that they felt the changes to their resources would be picked up by members because the guides are the most accessed resources on their website and because feedback from members on the guides *"is always very positive"*. PIF know that *"people use them, share them and download them"* because they see them referenced in health information, and know that members are referring other organisations to PIF. PIF can also gauge whether or not organisations are taking on board guidance by how many of their member organisations have the 'PIF TICK; a series of criteria for health information that can be measured. One of the desirable requirements for the evidence criteria is "use of patient data to support your evidence sources".

The aim of these changes was to influence PIF members to edit their health information, and as a result increase readers' understanding of the use of patient data in health information, and their trust in this. Based on the findings of the How to Talk About Data project, it was believed these impacts would come about with the emphasis on real people within health information because patient data "comes from real people and helps real people".

> *"It's the real people side of things… People trust people more than institutions, when it's clear who the data has come from it seems it has a face, it makes it more trustworthy"* – PIF representative

PIF also felt that the impact of these changes would depend on the communities being targeted, acknowledging that some communities have less trust in institutions, and therefore might need more explanation to trust patient data in health information. Additionally some communities are used to not being represented within health information, meaning it is important to explain that the patient data included people from within their community (e.g. a certain area of a city, an age group, an ethnic group etc.) where possible and accurate.

PIF also explained that some of its member organisations had been working on explaining the use of patient data to their readers *"for a long time"* meaning they *"probably aren't representative for the wider health information picture"*.

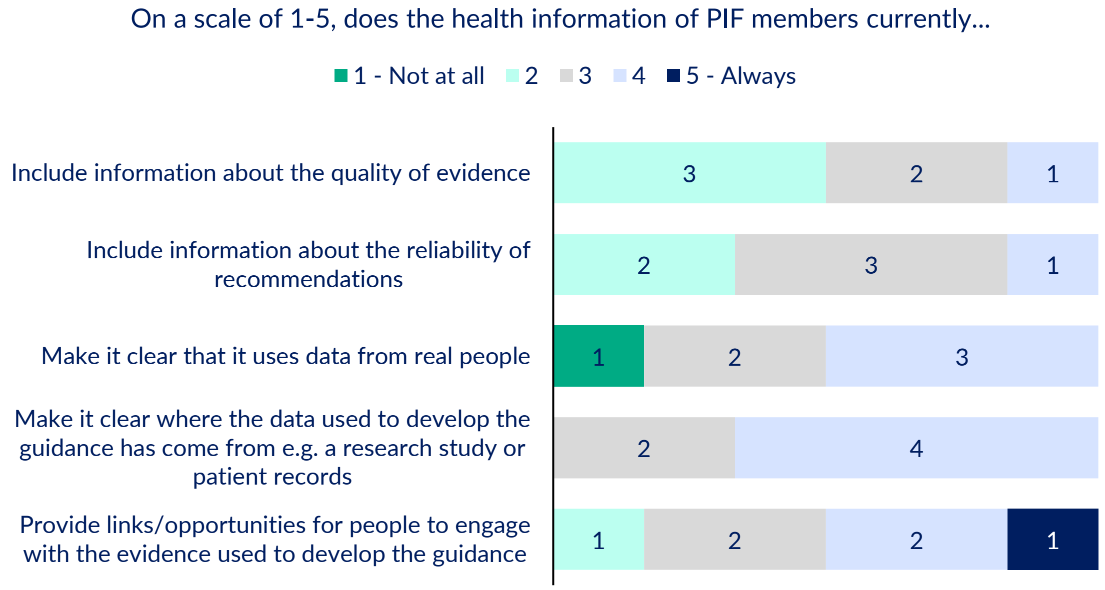
4.8 PIF member survey analysis

6 organisations completed the survey designed specifically for PIF members to understand what, if any, impact the changes in guidance would have in the health information they produce. Survey participants consisted of:

- **Type of organisation:** five charities and one NHS organisation
- **Location:** one in London, two North West, one West Midlands and two not specified
- **Number of employees:** three under 100, one between 100-500, two 1000+
- **Number of beneficiaries:** two 1000, two over 1 million and two not specified
- **Length of time as a PIF member:** three less than a year, one 2-3 years, two 3+ years.

PIF members were asked to rate their current health information. They were asked specific questions about how the use of patient data is explained in their health information. Responses to these questions are captured in figure 5 below.

Figure 5 – Current health information of PIF members

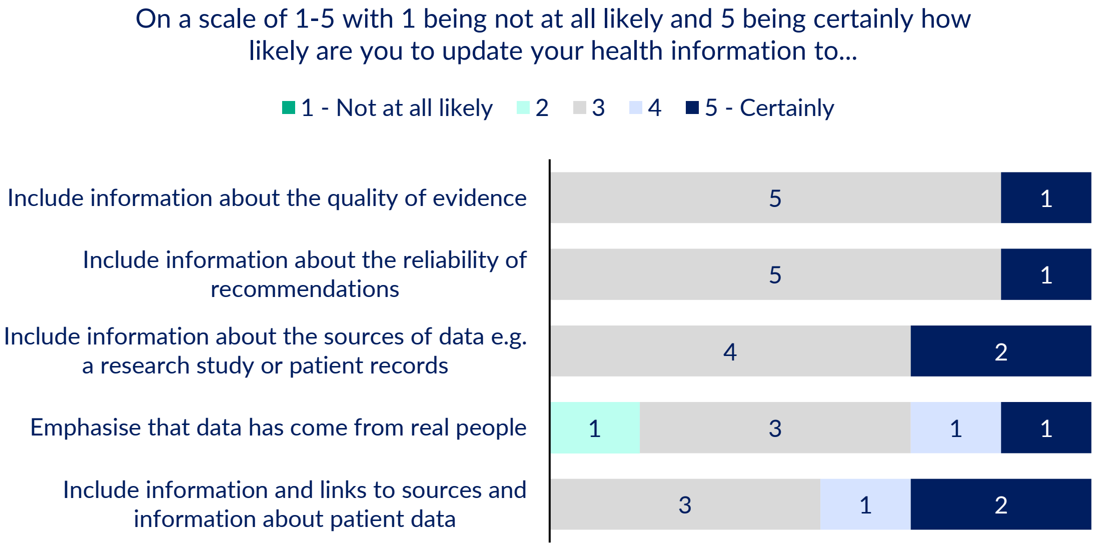


Awareness of PIF guidance on how to explain the use of patient data in health information was high with four out of six members aware. All of those who were aware of the guidance had read it. Two out of the four who had read the guidance had already made changes to the way they explain the use of patient data in their health information. These changes were described as:

> *“[We] use the principles set out in the guidance shared by PIF as part of PIF TICK scheme”.*
>
> PIF survey participant

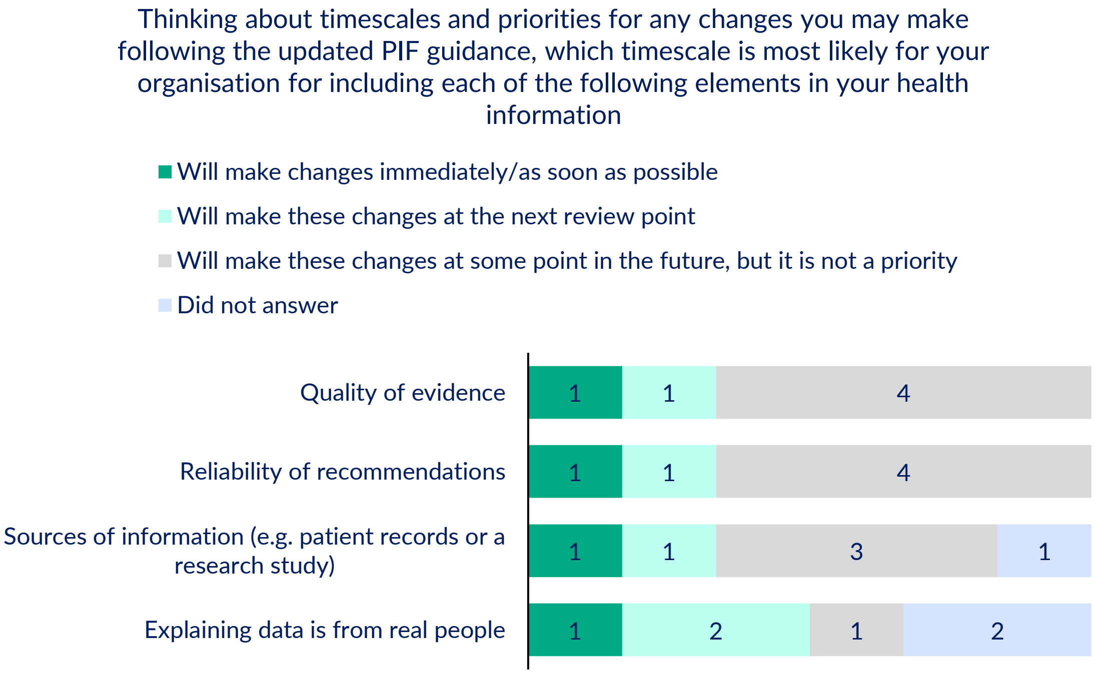
PIF members were then asked how likely they would be to make changes to their health information relating to the explanation of the use of patient data, and the timescales at which they would make these changes. PIF members most commonly responded neutrally (3 out of 5) to the question of how likely they were to update their health information. No one responded ‘not at all likely’, however only one or two responded ‘certainly’ to each factor. That a slight positive shift is seen in relation to organisations emphasising that data has come from real people is encouraging and is likely a result of the additional guidance described above. This may indicate that additional, explicit guidance on explaining the use of patient data would be useful to produce.

Figure 6 - Likelihood of change to health information as a result of updated PIF guidance



Regarding timescales, one organisation responded that they would make all changes ‘immediately/as soon as possible’. More commonly organisations expressed that they would changes ‘at some point in the future, but it is not a priority’. This suggests that PIF members are willing to make these changes and see that they are worthwhile, but more would need to be done to get these changes higher on their organisation’s agendas.

Figure 7 – Timescales for change of health advice



Members who were intending to make changes explained what they were hoping to achieve as a result of these. For their organisations, members were hoping to improve their own knowledge about data, and to be perceived as working transparently, producing health information that is accurate, reliable and that clearly states sources of evidence.

“[We want to] ensure our information is seen as reflecting the true situation for evidence relating to our advice”. PIF survey participant

For their target audiences, members were hoping to help increase people’s understanding of:

- How data is used
- Who data is referring to and where it has come from
- The robustness and reliability of data
- The health information that the organisation produces and therefore increase knowledge e.g. about a particular condition.

“Ensuring targets audiences are more aware of how data is used”. PIF survey participant

There were two organisations who explained that they were unlikely to make changes to their health information because:

- They already feel like they explain the use of patient data in their health information,
- They felt they had to give the explanation of patient data consideration to understand whether it was relevant in their field of work.

7. Impacts of the community of practice approach

Key findings

Perspectives of CoP members

- Members joined the CoP for a range of reasons, centred around learning from one another and a desire to improve their health information
- Some CoP members did make changes to their health information as a result of CoP membership, though most did not make changes during the timescale of the evaluation.
- Of those that made changes, some focussed on inclusion of data in health information, rather than inclusion of information about the use of patient data. Even transitioning to include more data in health information required a shift in approach for some CoP members.
- Benefits of the CoP included receiving feedback on updated health information, networking with other CoP members. Members felt the CoP had led to a long-term impact on how their organisation would produce health information.
- Suggestions for improving the approach included using CoP meetings to share examples of changes other organisations were making and increasing the number of organisations within the CoP to increase variety of expertise

Perspectives of UPD team

- The relational approach to recruiting CoP members was considered effective
- CoP members varied in their roles and seniority within their respective organisations, which affected their ability to implement changes to health information. Having two representatives from each organisation in future projects may help secure the right membership to deliver changes and ensure continuity in cases of staff turnover.
- The CoP was considered to provide useful networking opportunities and the inclusion of PIF was particularly valuable.

In addition to the impacts of changes to the health advice, the evaluation also aimed to understand the process of change, whether the community of practice enabled this change, any lessons from the health charities involvement and whether there were any other impacts for those involved. We sought to better understand the process through interviews with CoP members, interviews with the UPD team and through a final focus group held the with CoP which was also used to share and check emerging findings from the evaluation of the changes made to health information.

4.9 Perspectives of CoP members

Interviews were conducted with 6 CoP members to understand if and how changes had been made to health information following engagement with the CoP, the impact of these changes, and the overall impact of the CoP approach for members.

Why members joined the CoP

Members joined the CoP for a range of reasons, mainly centred around learning from each other, and wanting to improve their own health information. Reasons given included:

- Improve health information content
- Understand good practice in ways to communicate about data
- Improve organisational understanding of what makes health information successful
- To learn from other charities
- Opportunities to network and share expertise and ideas with people in similar roles
- Explore the use of patient data in health information as a positive opportunity rather than something to worry about
- Previous work with UPD in a different capacity.

Making changes to health information

Some CoP members did make changes to their health information to include details about the use of patient data as a result of CoP membership. However, most members had not made these changes at the time of the evaluation. There were a number of reasons for this:

For some members, this was due to the **timescales associated with internal processes** for changing health information and conflicting priorities regarding other changes that were happening to health information. For example, one CoP member was transitioning health information into an app-based format which took precedence over these changes within teams involved in adapting health information. Another explained that *"they came away [from the CoP meetings] feeling inspired, but then would get caught up in their day job"*.

Some organisations thought the **distinction between including data, including case studies, and including information about the use of patient data was blurry** and challenging to implement in practice.

There was some confusion around the specific focus of the CoP. Members thought it would have been **helpful to use CoP meetings to share examples of changes other organisations were making.** Members who were present at a session where UPD gave a worked example said this had helped them better understand the focus – *"Working through the example was great – that was when it clicked for me."* Other organisations felt that a template for health information or a check list of changes they needed to make would have been helpful as *"something a bit more active that we could rattle through"*. The scorecard developed for this evaluation can serve this purpose in the future.

Some of these organisations had made changes to include more **data** in health information, but not to include **information about the use of patient data**. Organisations who had included more **data** in their health information as a result of the CoP membership said that they wanted to demonstrate that the information on their website was evidence based, enhance trust in health information, and contextualise information for the reader. They noted the challenge in maintaining accessibility of information and wanted to avoid making information too academic or overwhelming while working to include statistics to support statements on their website. Even just transitioning to include more data in health information required a shift in approach for some CoP members.

Other organisations felt that they could not make changes because there was not sufficient patient data on the conditions they were working on, again meaning the focus for them was on **inclusion of data, rather than inclusion of information about the use of patient data.** As a result of this one organisation made changes to include more **personal stories** in health information.

Some members had experienced a **high degree of turnover in staff** at their organisation and as a result the organisation's representative had changed during the course of the CoP. This had delayed the process of learning about the suggested changes to be made and integrating them into health information.

Benefits from the CoP

CoP members who did make changes to their health information explained that they **received feedback from the CoP on their updated health information** which was beneficial.

Networking with other CoP members has been beneficial to some CoP members. An important part of this has been hearing about the ideas of other organisations and challenges that they have faced in explaining how patient data is used in their health information and learning from this.

"I love the meetings we have had and the drop-in sessions. They have been really helpful for us to think about how we are doing things… talking to others and hearing their perspectives on how they are doing it and putting our heads together… it has been helpful in terms of networking, [another CoP member] had some information I hadn't seen before which has now informed our research." – CoP member

"It's always really useful to network with other organisations working in this field, always opportunities to collaborate, really important to have collaborative and cross sector working in health information" – CoP member

One member explained that whilst the CoP hasn't been particularly influential so far, they felt that **the findings from the CoP would have a wider impact** once results had been published. Members also felt having preliminary findings from the evaluation would be **useful to persuade colleagues** of the importance of including discussion around the use of patient data in health information.

"When outcomes are published and people can see the impact this will have a wider influence" – CoP member

"It's part of a bigger picture in terms of creating really valuable content, I'm feeding back what I've learnt into meetings and sharing it with [my colleagues]" – CoP member

Members also felt the CoP had led to a **long-lasting impact on how organisations produce health information** and were keen to continue implementing the changes that they had learnt about during this process.

"The changes we implemented will continue which is great and ties in nicely with other work on activating behaviour change" – CoP member

Suggestions for improving the CoP approach

CoP members faced certain challenges, leading to a range of suggestions for how the CoP approach could be improved.

Some members felt **group meetings could have been shorter or more streamlined**, and that there could have been **more one-to-one support**. Over half of CoP meetings however were one hour or less and one-to-one support was offered by UPD on a number of occasions. There was also acknowledgement from CoP members that at times they might have asked for more support, but in reality, **not actually had time to take this up**.

> *"Meetings have been a bit cumbersome, they have taken a little bit of time… I might have preferred some slightly more targeted one-to-ones… I would want a mix; shorter group meetings that keep really focused and more personal targeted conversations where the UPD team can work with me through the steps I need to take to get this done".* – CoP member

One organisation expressed it would have been useful for UPD to **circulate agendas/session materials in advance**, however this was done by the team, which suggests CoP members may not have had the time to review the documents they were receiving in advance.

Another felt that there could have been **more organisations within the CoP** to create a *"critical mass [and bring] more variety of expertise and areas"*

Some members felt **more interaction with the teams actually producing and editing health information** would have been useful. Again, the UPD team explained that they had offered this to CoP members, which suggests that members did not have the time to take up these offers or organise sessions with teams internally. Members and UPD staff felt that the end of the project could be a good opportunity to bring together content producers for a workshop on how to discuss the use of patient data within health information.

4.10 Perspectives of UPD team

Four members of the UPD team were interviewed to understand their perspectives of the impact and process of the CoP. Three of the four people interviewed had transitory involvement in the project either due to the remit of their role or, for two people, being on a rotation across different areas of the Wellcome Trust, where UPD is based. Interviews lasted approximately one hour. At the time of interviews none of the UPD team had sight of changes to the health information made by the CoP members and so were not able to comment on these or potential impacts of change. The following themes emerged from the interviews.

Development and composition of the community of practice

The membership of the CoP was built through existing relationships that the health charities had with either UPD or Health Data Research UK (HDRUK) and, as a result, comprised of charities which already had an interest in the use of patient data but were not necessarily communicating how it was used. It was felt across the UPD team that, given both the nature of the changes being suggested to health information and the timing of the project in the midst of the Covid-19 pandemic, this relational approach to recruitment was the right one and that a wider communications piece, for example using an email distribution list, would not have been successful in establishing the group.

It was reflected that those people attending the CoP as representatives of their organisation varied substantially in terms of their role, seniority, and by virtue of these, their ability to decide and make changes to health information. It was felt that this might be particularly the case for larger charities with governance structures creating more ‘distance’ between decision making and implementation or where more senior staff initially attended the CoP before delegating this to colleagues. One member of the UPD team identified a “sweet spot” in one member who headed the department responsible for developing health information.

It was also identified that staff turnover within the CoP members represented a challenge in providing continuity in membership. There was a belief that internal handover of the project within health charities where there was staff turnover was not provided and therefore impacted upon understanding of the aims of the CoP. This resulted in the purpose of the project having to be revisited multiple times. For future iterations of the project, or similar projects, it may be desirable, despite the resource implication, to request two representatives from each organisation to attend the CoP meetings, particularly where decision-making and implementation may be separated. This would provide consistency in how the purpose of the project is communicated within health charities, the correct membership to deliver changes, and ensure better continuity where staff turnover occurs.

UPD staff also felt that there were issues in communicating what support was available to the CoP members because they felt like they were “offering to meet people, to run additional sessions” etc. but these were not being taken up. They explained that there may be more they could do as the host organisation of the CoP to fulfil the needs of the members but could not identify what this might be.

The impact of the community of practice approach

With the exception of one member there was little experience in the UPD team of delivering or being a part of a community of practice, although team members were aware that this was an approach used previously in other areas of Wellcome. The community was co-designed with original charity members and those that joined after this were able to influence how it was delivered. Delivery included the use of more didactic methods at the 'mid-way' point of the process (when meetings of the full CoP began) to share previous Data in Health Information research and findings and provide examples of how to change health information, as well as opportunities for members to discuss progress and collectively problem solve and individually approach the UPD team for support. It was felt that this approach and this flexibility provided a useful for way the members to become involved in discussions of how to explain patient data without pressuring them to make changes to specific deadlines. Without this approach it was suggested that attrition from the community may have been higher, particularly given the resourcing pressures experienced due to the pandemic. It was also noted that the CoP provided useful networking opportunities and that the inclusion of PIF was particularly valuable.

Despite the strengths and additional benefits of the approach, the lack of change within health information at the point of interview meant that UPD team were not able to definitively identify impacts in relation to changes in health information. It was acknowledged that the changes being sought were nuanced and do not necessarily require substantive changes to the advice given and that this in itself presents challenges. This is also reflected in the feedback from CoP members and our findings in relation to changes that have been made. However, the prolonged engagement of members and the other benefits highlighted would suggest that the CoP approach is of value.

8. Conclusions and recommendations

It is apparent that even small changes in the way patient data is explained were noticeable and influential to the reader's perception of the health advice given. Consistently for both survey and focus group participants the additional explanations provided in example B increased levels of trust and credibility in information. Citing the NHS as a source of data was particularly useful as it is seen as a trustworthy and credible source and that including this information may help shift a prevailing (negative) narrative around the potential risks of sharing data, by emphasising its use in NHS provision. Whilst for a minority this addition risks exacerbating concerns about data sharing, overall there was an expressed preference for health information which demonstrated that the data used had come from people.

Including explanations of patient data use was also linked with increasing the knowledge of the reader as to how data is used outside of people's direct care. Whilst it was noted in focus groups that this might be a start of a process which takes years, some members explicitly felt that such additions would increase data literacy.

This evaluation also indicates that this additional explanation of patient data is likely to influence the reader's behaviour in relation to engaging with data. Both survey responses and focus groups demonstrate that, for many, the additions prompted further curiosity as to how data was used and provoked questions. The importance of providing sources to enable the reader to find out more was also a consistent recommendation from those taking part. Whilst there is a clear desire for more information, a balance needs to be struck between accessibility and detail and, although beneficial, it was often suggested that even small additions could have a detrimental effect on accessibility.

Survey participants also indicated that, because of increased trust in the information, they would be more likely to pay attention, to follow, and to share the health advice.

Whilst the community of practice members have faced challenges in making changes to the health advice it would appear that the community of practice approach is a valid and effective way of influencing and supporting change. CoP members found a range of benefits both in relation to learning and sharing good practice in explaining patient data, as well as opportunities to network.

CoP members believe that the findings from this evaluation will be persuasive in affecting future changes in relation to explaining the use of patient data. It may be anticipated that as the evidence base of the value of explaining patient data grows, the easier it will be for organisations to prioritise such changes. With this in mind we make the following recommendations in relation to both how to continue to develop understanding around the use of patient data and how to support change.

Developing understanding of patient data

1. Given that the citation of the NHS as a source of data improves transparency about how patient data is used and is perceived to make the information more credible we would recommend that, where relevant, that this change is prioritised in any future change in health information.

2. This evaluation indicates that including explanations of the use of patient data has positive impacts in both the understanding of, and engagement with, data. That including explanations makes the information seem more credible may impact upon the readers' behaviour in relation to the health advice, but this is untested. We recommend that this evidence base is developed with the use of contextually relevant health information (i.e. health information relating to conditions or illnesses which are relevant to the reader through the inclusion of such explanations in relevant health information at different points of care (e.g. diagnosis, treatment options, recovery, or maintenance of health).

3. Findings from our focus groups indicated that the impact of changes to health information may depend upon the communities that the readers are from. Differences in trust in health institutions and representation within health information amongst minoritised communities are likely to negatively impact upon trust and perceptions of relevance. We would recommend testing this within specific minoritised communities.

4. There were anecdotal concerns that inclusion of explanations of how patient data is used may increase concern about how patient data is used. This could be mitigated by also providing links to existing information in relation to anonymisation and pseudonymisation in research processes.

5. There were also concerns within focus groups and CoP members that even small increases in information will negatively impact accessibility, although it should be noted that this was not an identified issue for any focus group or survey participants. It is recommended future

evaluation specifically include people who may experience accessibility issues or involve health charities such as those for people with sight loss or learning difficulties or disabilities.

Supporting change in the explanation of patient data

5. **Review community of practice arrangements.** Whilst we believe that a CoP approach is still an effective way to support change in this area, there are specific recommendations from current CoP members and learning from the UPD team. These include:
    a. **Consideration of membership** possibly including more than one member of staff from organisations to provide continuity, support internal communications of the aims of the changes and balance decision making and colleagues who will develop the information. It was also suggested a bigger community might be beneficial
    b. **Meeting structure** a preference for shorter, more targeted meetings at different times of day. Ownership of the community could be shared across its members from the outset and practices such as check in and check out to gauge levels of understanding and intent might prove useful.

6. **Promoting the evidence to encourage future change.** We would suggest a webinar or similar event to share the findings of the evaluation and consider establishing another community of practice or similar working group to support changes with other health charities/organisations.
7. **Continue to produce explicit guidance on** explaining the use of patient data and explaining the value of this and distributing this to organisations

Appendix 1 - Evaluation Framework

Figure 8 The original evaluation framework

Evaluation aim	Evaluation objective	Evaluation Questions	Source(s) of information					
			Review of pre & post health literature	Interviews with CoP members & UPD staff	Interviews with beneficiaries	Focus groups with beneficiaries	Website analytics	Survey
1. How does explaining the use of patient data impact upon people's knowledge of the use of their data outside of their direct care?	Has people's understanding of how patient data is used (outside of direct care) changed as a result of its inclusion/discussion	What is people's understanding of how patient data is used? (baseline)			x	x		x
		What are people's current perceptions of the use of patient data (trust/security, value etc) (baseline)?			x	x		x
		How does explaining patient data in health literature impact upon people's understanding of where health advice comes from?			x	x		x
		How does explaining the use of patient data impact upon people's understanding of how their data is used?		x	x	x		x
		Has explanation changed people's perceptions of the use of patient data (eg trust/security, value etc)?			x	x		x
	Has people's engagement/interactions with health information changed with the inclusion of information about patient data?	Are people more likely to seek out further information to increase understanding of the use of their data?		x	x	x	x	
		Are people more likely to trust and champion patient data use?		x	x	x		
2. How has the inclusion of/explanation of patient data impacted upon beneficiary behaviour in relation to the advice provided?	How has beneficiary use of health information changed due to the inclusion of information about patient data?	To what extent do people pay attention to and take action on health advice provided?			x	x		x
		Are people more likely to pay attention to health information when information/discussion about patient data is included?			x	x	x	
		Are people more likely to take action relating to that health information when patient data is included and explained?			x	x		
3. What has been the impact of the CoP approach for its members?	What has been the impact of the Community of Practice approach?	How effective has the CoP approach been to supporting changes in the explanationion of patient data in health literature?		x				
		Are there any other unintended benefits or challenges of the CoP approach for members?		x				
		Other enablers or challenges experienced in updating health literature in relation to patient data use?		x				
Understand the extent to which health literature follows DiHI good practice?		How closely does the discussion of the use of patient data follow best practice guidance developed by UPD	X					
How does good practice guidance provided by PIF on explaining patient data impact the health literature produced by PIF members/partners (in relation to including and explaining the use of patient data)	Has member/partner information changed (or is there intention to change) in the way it explains patient data use as a result of the PIF guidance?	How is the use of patient data currently explained in health information			x	x		
		What changes have or are planning on being made as a result of PIF's updated guidance?			x	x		
	What are member/partners reasons for any changes/intent to change	What are the outcomes members/partners are hoping to achieve for their organisation as a result of any changes			x	x		
		What are the outcomes members/partners are hoping to achieve for their target audience as a result of any changes			x	x		

Figure 9 The actual evaluation framework used adapted in response to CoP members changes and ability to engage with the evaluation

Evaluation aim	Evaluation objective	Evaluation Questions	Source(s) of information			
			Review of pre & post health literature	Interviews with CoP members & UPD staff	Focus groups with beneficiaries/public	Survey
1. How does explaining the use of patient data impact upon people's knowledge of the use of their data outside of their direct care?	Has people's understanding of how patient data is used (outside of direct care) changed as a result of its inclusion/discussion	What is people's understanding of how patient data is used? (baseline)			x	x
		What are people's current perceptions of the use of patient data (trust/security, value etc) (baseline)?			x	x
		How does explaining patient data in health literature impact upon people's understanding of where health advice comes from?			x	x
		How does explaining the use of patient data impact upon people's understanding of how their data is used?		x	x	x
		Has explanation changed people's perceptions of the use of patient data (eg trust/security, value etc)?			x	x
	Has people's engagement/interactions with health information changed with the inclusion of	Are people more likely to seek out further information to increase understanding of the use of their data?		x	x	
		Are people more likely to trust and champion patient data use?		x	x	
2. How has the inclusion of/explanation of patient data impacted upon beneficiary behaviour in relation to the advice provided?	How has beneficiary use of health information changed due to the inclusion of information about patient data?	To what extent do people pay attention to and take action on health advice provided?			x	x
		Are people more likely to pay attention to health information when information/discussion about patient data is included?			x	
		Are people more likely to take action relating to that health information when patient data is included and explained?			x	
3. What has been the impact of the CoP approach for its members?	What has been the impact of the Community of Practice approach?	How effective has the CoP approach been to supporting changes in the explanationion of patient data in health literature?		x		
		Are there any other unintended benefits or challenges of the CoP approach for members?		x		
		Other enablers or challenges experienced in updating health literature in relation to patient data use?		x		
Understand the extent to which health literature follows DiHI good practice?		How closely does the discussion of the use of patient data follow best practice guidance developed by UPD	X			
How does good practice guidance provided by PIF on explaining patient data impact the health literature produced by PIF members/partners (in relation to including and explaining the use of patient data)	Has member/partner information changed (or is there intention to change) in the way it explains patient	How is the use of patient data currently explained in health information			x	
		What changes have or are planning on being made as a result of PIF's updated guidance?			x	
	What are member/partners reasons for any changes/intent to change	What are the outcomes members/partners are hoping to achieve for their organisation as a result of any changes			x	
		What are the outcomes members/partners are hoping to achieve for their target audience as a result of any changes			x	

Appendix 2 – Participant demographic data

7.1 Focus group demographic data

In total five focus groups were held between the 25th of February and the 14th of March 2022. One group was facilitated with the patient expert panel with the MS Trust whilst, the other four groups were recruited via Rocket Science social media and publicised via Use My Data and Health Data Research UK. All groups were held virtually using Microsoft Teams and followed the same topic guide. In total 31 people attended the five groups; all were offered payment for their participation in line with National Institute for Health Research guidance. At the end of each session participants were asked to anonymously share demographic information relating to their age, gender, and ethnicity. As this was optional, response rates to each of these questions vary. The demographic information we received is outlined below.

Figure 10 - Ethnicity of focus group participants Based upon 2011 census data there is greater representation of people from Black and Asian ethnic groups than the general population (n=22)

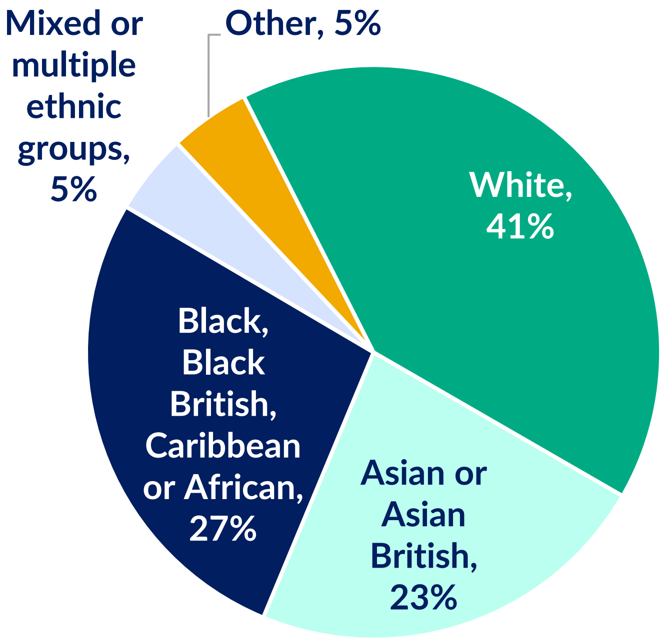


Figure 11 – Gender of focus group members. There is underrepresentation of women and other genders than man within the focus group sample (n=22).

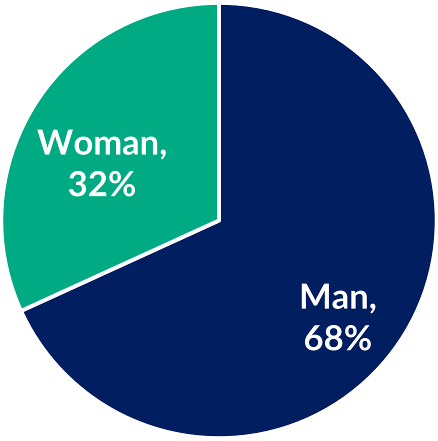
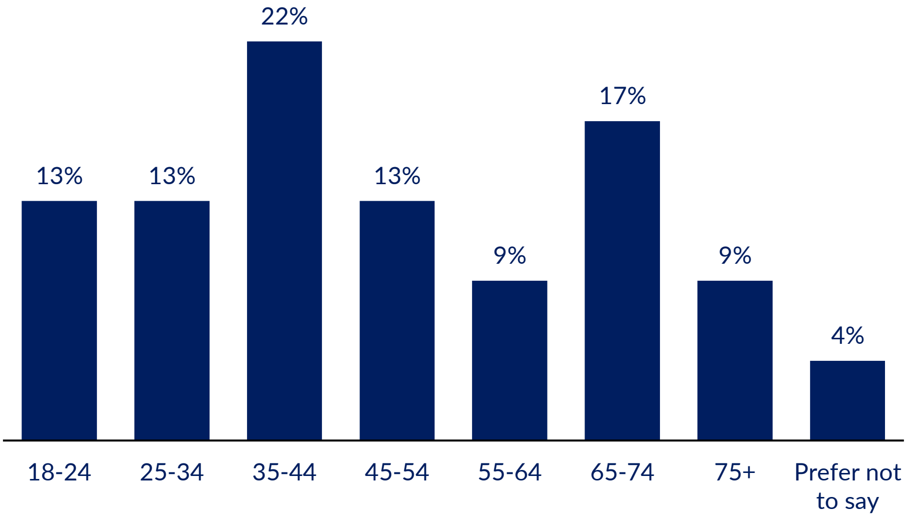


Figure 12 – Number of focus group participants across age groups the age structure of focus group participants is broadly representative of the general population[7].



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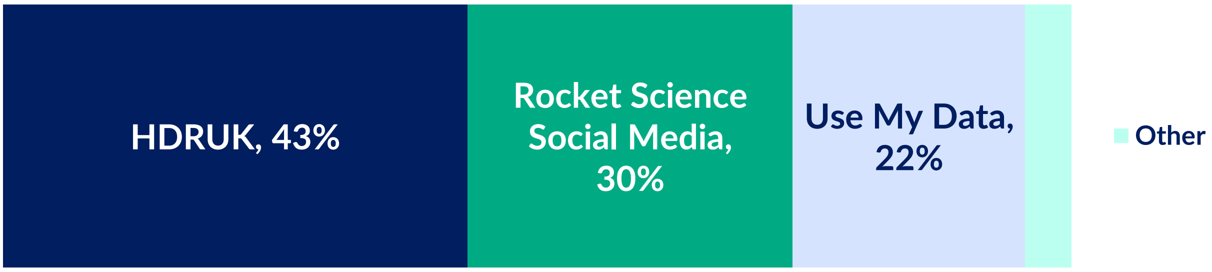
[7] ONS Early indicators of UK population size and age structure, April 2021 [Early indicators of UK population size and age structure - Office for National Statistics](). Last accessed 16/03/22.

15 (65%) of the group participants learnt about the research through their contact with either HDRUK or Use My Data, suggesting an interest in and possibly above average understanding of the use of patient data.

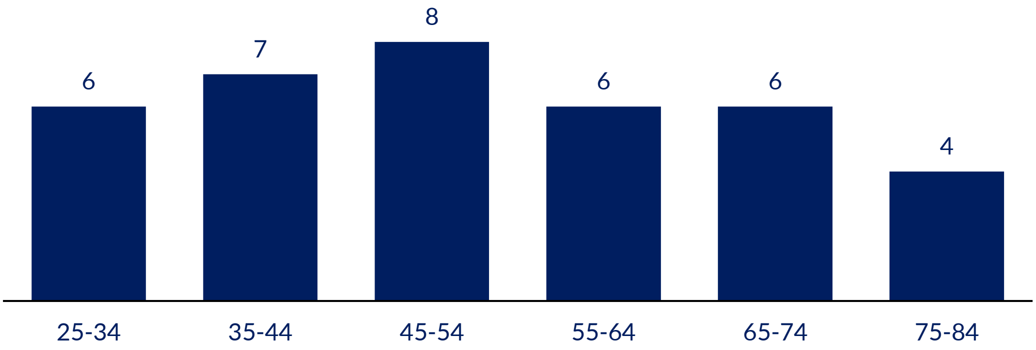
Figure 13 – How focus group participants learnt about the research.



7.2 Survey demographic data

37 responses were received to the survey in total. As responses to questions were not compulsory, in some cases the number of responses does not sum to 37. Where this is the case, the number of responses is provided (e.g. n=35).

Figure 14 – Number of survey participants across age groups (n=37). The age structure of survey participants is broadly representative of the general population[8].



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[8] ONS Early indicators of UK population size and age structure, April 2021 Early indicators of UK population size and age structure - Office for National Statistics. Last accessed 16/03/22.

Figure 15 – Gender of survey participants. There is clear under representation of men within the survey participant sample (n=37), in contrast with the demographics of focus group participants.

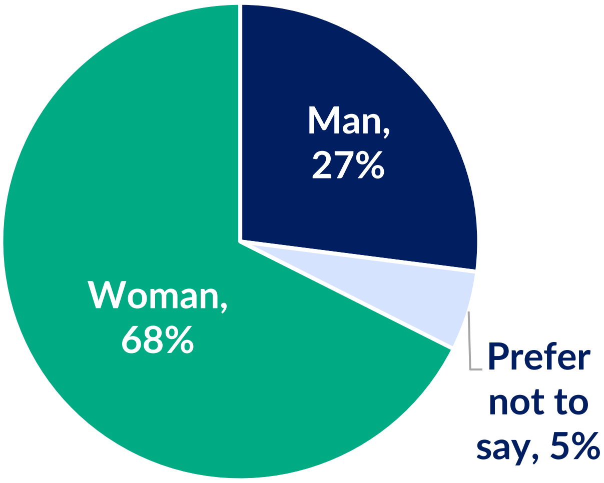
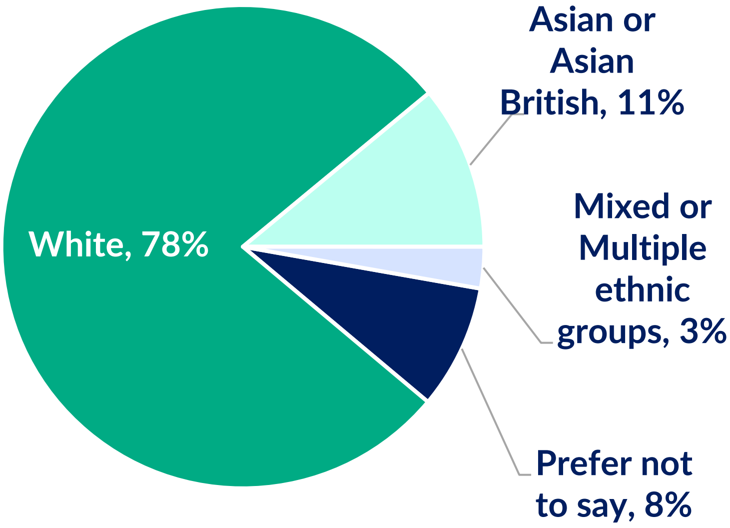


Figure 1 -Ethnicity of survey participants. Based upon 2011 census data there is greater representation of people from Asian ethnic groups and mixed/multiple ethnic groups than the general population among survey participants. Those from Black ethnic groups were underrepresented in the survey sample (n=37)



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